The Health Care Improvement Foundation (HCIF) launched the Health Equity Data Strategy (HEDS) Collaborative in 2021, bringing together Partnership for Patient Care (PPC) contributing organizations with the common goal of decreasing disparities in health outcomes in our communities across the Southeast Pennsylvania region. The HEDS collaborative focuses on the collection, stratification, and utilization of race, ethnicity, and language (REaL) and sexual orientation and gender identity (SOGI) data, which serves as a critical first step to addressing inequities in care and outcomes.

This survey was administered for the purpose of gathering data on how participating organizations collect and utilize SOGI demographic information. Results from this survey will allow for participating project teams to assess their current data and practices, identify areas for targeted intervention, and measure progress during the course of the collaborative. Examining survey results in aggregate gives participants the opportunity to benchmark themselves against other organizations in the collaborative. Project teams are encouraged to use survey results for making improvements, and over time, to expand those efforts across all care settings and system-wide to have the purposeful and broad impact on the communities they serve.

Survey Administration

6 regional hospitals and health systems participated in survey

Survey questions were derived from national recommendations on SOGI data collection

Launched in June 2023 with 5 weeks for respondents to complete

Approximately 27 questions categorized into 6 core sections:
Background, Data Collection & Workforce Training, Technological Questions, Data Accuracy & Completeness, Data Stratification & Usage, and Communicating Findings & Leadership Support

For any questions, please contact Liz Owens, eowens@hcifonline.org
Survey Findings

Below is a summary of seven key findings from the survey. This highlights both strengths and opportunities for improvement identified through survey analysis. Please note that findings may represent a sample of survey responses as not all survey questions were required or applicable. Six organizations responded and are represented below.

Scope of Data Collection
83% of survey respondents reported collecting Sexual Orientation and Gender Identity (SOGI) and Sex Assigned at Birth Data (SAAB) data from at least some of their patients. The majority of organizations offer robust and diverse options for SOGI data collection, but there is opportunity for improvement in diverse and self-identifiable response options.

Methods of Data Collection
Electronic self-identification via the patient portal and verbal collection were the main mechanisms for collecting SOGI data, and the registrar was the most common personnel trained to collect SOGI data followed by clinicians, schedulers, and patient access representatives. 100% of respondents reported that SOGI and SAAB are structured fields in their electronic medical record (EMR), with one organization reporting that these fields are required.

Verification of Data
Data verification is low and undeveloped for organizations, with half of the respondents stating that they have not started the process or are in the beginning stages. There is opportunity for improving the methods of which data is verified, such as validating data against local demographics.

Patient Experience & Outcomes
Patient engagement, communication, and input is low for responding organizations, with the majority not engaging patient and family advisors in the SOGI data collection process. Half of the respondents have experienced complaints from patients about SOGI data collection, especially surrounding gender identity. The majority of respondents do not communicate patient outcomes stratified by SOGI to internal leadership, staff or external partners, thus there is opportunity to improve this communication.

Data Utilization & Interventions
Data implementation and utilization is low, and therefore interventions are not robust. There is a future opportunity to identify disparities based on stratification of measures; although, the lack of adequate SOGI data may be a current contributing factor.

Workforce Training
The majority of organizations have basic workforce training, though there is opportunity to build out workforce training programs to address additional components of SOGI data collection to include: training staff to discuss protections of SOGI data with patients, involving patient and family advisors in the development of workforce training, and evaluating their workforce training program annually.

Organizational Involvement
Leadership is involved in SOGI initiatives by providing resources to establish infrastructure for improved data collection, though there is opportunity for leadership to be involved in setting goals and developing interventions. SOGI data collection is interdisciplinary at institutions involving various departments.